Single Parents with disabled children Issues, challenges & policy actions

Briefing

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Introduction

One Parent Families Scotland (OPFS)¹ is Scotland's national single parent organisation. OPFS provides expert information, advice, and family support, along with training activities and employability programmes tailored to the needs of single parent families.

Our vision for Scotland is one where single parent families are celebrated in all their diversity, are treated fairly and live free from discrimination and poverty. We work to amplify the voices of single parents recognising their dual responsibility as both caregivers and providers and together challenge stigma, poverty, and inequality to achieve change.

This report will consider the main barriers which affect single parent families who have the additional challenge of bringing up a disabled child/child. Research by Scottish Government shows that 40% of children in poverty in single parent families have a disabled adult or child in the household. This means that we have a statistical basis for regarding the inequalities faced by disabled people as a priority issue for One Parent Families Scotland.

Single parents, the majority of whom are mothers, are on call 24/7 for their children, often with no respite. The pressure is often compounded when one or more of their children is disabled. A low income and a lack of wider family support can make these situations extremely challenging. The impact can be significant, for example on the parents' health and wellbeing, and can limit the opportunity for them to take up paid employment.

OPFS is a leading member of the "Scotland That Cares" campaign which describes unpaid carers as, "invaluable to us all, but are too often made invisible, undervalued

¹ One Parent Families Scotland, NK. Who are One Parent Families Scotland?

and ignored" ². Following a successful campaign backed by over 70 organisations including leading Scottish charities, think tanks and trade unions, the Scottish Government has proposed a new, dedicated National Outcome on care³.

There is a need for greater recognition of the structural limitations parents caring for a disabled child or children face, the sources of poverty they encounter, and the subsequent policies needed to address these concerns. It is only by listening to the voices of single parents, who look after a child with a disability, that those designing and actioning relevant policies can gain a fuller appreciation of the real issues and solutions required.

Single parents with a child or children with a disability also face dealing with a social security system where 'conditionality' is playing a bigger role in welfare reform. As well as having to juggle their dual roles of main unpaid carer and breadwinner, single parents with a disabled child are further disadvantaged by a social security system which places an inflexible mandatory obligation of participation in the labour market despite personal circumstances. The impact of benefit conditionality on single parent families' financial circumstances is a major concern for OPFS, as we hear first-hand from parents about the impact on family wellbeing.

A carer who provides at least 35 hrs. a week caring for a child with disabilities and is in receipt of certain disability benefits is normally exempt from 'conditionality'. However, under Universal Credit many families with disabled children will be worse off, as extra disability payments are being cut by more than 50% for most disabled children. "Contact A Family" estimate that families with disabled children are more likely to be worse off than any other families, with all the increased debt, stress, and ill-health this brings⁴.

The report will conclude by making recommendations focused on addressing the often-intolerable situations single parents with a disabled child face.

² <u>Scotland that Cares, 2023. Invaluable but Invisible: why Scotland needs a new national outcome on care.</u>

³ <u>Scottish Care, 2024. A Scotland That Cares Campaign Success - National Outcome on Care.</u>

⁴ UK Parliament, 2023. Evidence on Universal Credit Update. Written evidence from Contact a Family.

One parent families in Scotland: a profile

- The majority of single parents are women in their 30's and 65% are in employment⁵
- 4 out of 10 children in poverty in Scotland live in a single parent family –
 90,000 children⁶
- Poverty rates for children in single parent families are twice as high as those in couple families. 39% couple parent families vs 19% single parent families⁷.
- Fewer than 2% of single parents are teenagers the median age is 388.
- 92% of single parents are mothers; therefore, gender is a key issue⁹.
- There are around 144,000 single parent families in Scotland. This makes up 25% of all families and 39% of all children in single parent households are living in poverty¹⁰.

The Scottish Governments six child poverty groups

The <u>Scottish Government's Tackling Child Poverty Delivery Plan</u> identifies six priority groups for action who experience higher than average levels of child poverty:

- · Lone parent families
- Young mothers (under 25)

⁵ OPFS, 2024. Media - Key Statistics.

⁶ <u>Scottish Parliament, 2021. One Parent Families Scotland Submission. Education, Children and Young People Committee.</u>

⁷ OPFS, 2022. Media: Key Statistics.

⁸ Gingerbread, 2024. Single Parent Facts and Figures.

⁹ Gingerbread, 2024. Single Parent Facts and Figures.

¹⁰ OPFS, 2022. Living Without a Lifeline.

- Larger families (with 3 or more children)
- Minority ethnic families
- Families with a baby (under one)
- Families with a disabled adult or child¹¹.

This follows from the <u>Child Poverty (Scotland) Act 2017</u> which enacted into law a statutory duty for the Scottish Government to produce a delivery plan for tackling child poverty.

The Act stated that the delivery plan must set out what (if any) measures Scottish Ministers propose to take in relation to children living in households whose income is adversely affected, or whose expenditure is increased, because a member of the household has one or more protected characteristics, and children living in single-parent households¹².

The child poverty rates amongst each of these groups are as follows:

- Lone parent families 38%.
- Young mothers (under 25) 55%.
- Larger families (with 3 or more children) 32%.
- Minority ethnic families 38%.
- Families with a baby (under one) 34%.
- Families with a disabled adult or child 29%.

Scottish Government analysis also finds that children often belong to more than one of the priority groups. Family Resources Survey¹³ found that of the six priority groups, the one which children in single parent families are most likely to belong to is households with a disabled adult or child. Of children in poverty in single parent families:

• 40% have a disabled adult or child in the household.

¹¹ Scottish Government, 2022-2026. Bright Start, Bright Future's - Tackline Child Poverty Delivery Plan.

¹² Scottish Government, 2017. Poverty and Social Justice.

¹³ Family Resources Survey, 2018.

- 19% are in larger families.
- 17% have mothers under 25.
- 10% have a baby in the household.
- 6% are in a "non-white" household.

These figures indicate that belonging to a single parent family increases the risk of poverty among the other priority groups.

This data is useful in informing our understanding of the demographics of single parent households. We, at One Parent Families Scotland and across any services aimed at single parents, can use this knowledge to ensure that our work is representative in addressing the needs and experiences of single parents.

Disability

The term, 'disability' can be defined differently by people, agencies, and institutions. For instance, the medical definition focuses on the person's disability. The social model, on the other hand, defines disability as a social phenomenon in which structures of society by their very nature are oppressive, create inequality and exclude those who do not conform to the norm¹⁴.

Importantly, social structures are not an inevitable negative force in people's lives. They can be changed and indeed, have the potential to improve people's quality of life and outcomes. As the social model concludes, society is structured towards the needs of the able-bodied, not people with disabilities. A single parent responding to a recent OPFS survey describes her experience:

¹⁴ Thomas, C. 2004. How is Disability Understood? An Examination of Sociological Approaches. University of Lancaster, UK, Disability & Society, 19 (6).



... although my daughter's disability benefit will hopefully continue as PIP payments once an adult, my other benefits will drop significantly- my daughter will continue to need me to look after her as she did as a child. She won't be able to earn/work or live independently. I'll experience a drastic cut in our household benefits, yet her care needs remain the same, or may be greater. I'm currently self-employed earning a low income due to my reduced ability to earn due to being the sole parent of a child with complex needs. I feel like a failure, but we are let down by a rigid system...

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The Financial Fairness Trust has recently found that, in the UK, households which include a disabled person are more likely to report being anxious when thinking about their financial situation (69% disabled vs 54% non-disabled), have low levels of financial confidence (47% vs 28%), have no savings (38% vs 22%), find it a constant struggle to pay bills (30% vs 13%) and owe money on a higher number of credit cards (11% vs 7%). Reflecting on the impact of the cost-of-living crisis, disabled households were more likely to have received financial help from friends and family (15% vs 7% non-disabled households¹⁶

For many Scottish families living with a disabled child, there are many positives, not least the possibility of caring for a loved one by developing resilience, determination and family cohesion with the support and encouragement of the community. However, negative stereotypes of low expectation, prejudice, social avoidance, and victimisation are still prevalent ¹⁷. The outcome is often characterised by stress, financial pressures, and poor mental health.

¹⁵ OPFS, 2022. Living without a Lifeline.

¹⁶ Financial Fairness Trust, 2022. Facing Barriers: Exploring the relationship between disability and financial wellbeing in the UK.

¹⁷ Babik, I; Gardner, E. 2021. Factors Affecting the Perception of Disability: A Developmental Perspective. Frontiers in Psychology.

A financial profile of families living with a disabled child in the UK

The disability organisation Scope have published the following research¹⁸,

- On average, disabled households (with at least one disabled adult or child)
 need an additional £975 a month to have the same standard of living as non-disabled households.
- If this figure is updated to account for inflation over the current period
 2022/2023, these extra costs rise to £1,122 per month.
- On average, the extra cost of disability is equivalent to 63% of household income after housing costs.
- The average extra costs rise to £1,248 per month where there are two
 disabled adults in the household and at least two children. And for
 households with one disabled adult, one non-disabled adult and at least one
 child, the average extra cost is £634.
- 99.1% of disabled children live at home and are supported by their families.
- Half of parents of disabled children are unable to work and have experienced poverty, because of lack of support for their child.
- Three in four parents have had to give up employment or their whole careers, due to lack of support.
- Seven out of ten parents said their disabled children's health had deteriorated because of lack of support.
- Only one in five felt their family received the support needed for their child to fulfil their potential.
- Over a third (38%) of parents have experienced marriage/relationship breakdown in the last 12 months because of lack of support for their disabled child.

¹⁸ Scope, 2023. Disability Price Tag 2023: The extra cost of disability.

- 84% of mothers of disabled children do not work, compared with 39% of mothers of non-disabled children. Only 3% of mothers of disabled children work full-time¹⁹.
- Disabled children are amongst the most likely to experience poverty, and children from poorer backgrounds are more likely to become disabled than those who are better off²⁰.

Living without a lifeline

The OPFS report, 'Living Without a Lifeline,'21 a wide-ranging consultation asked Scottish single parents about the day-to-day issues that affect their lives. It asked what they thought Governments should do to support their families and what OPFS should prioritise in our service delivery. This resultant report describes the grinding poverty faced by many single parent families. In some cases, mothers are going without food and struggle to pay essential bills. Isolation, anxiety, depression, and suicidal thoughts are predominant themes. The report also highlights that the COVID-19 impact has not been borne equally.

We know from our support and advice services that many parents we support are disabled themselves or have disabled children. The Living Without a Lifeline report highlighted that 56.6% of single parent respondents and 35.9% of their children have a disability which limited daily activities and education²². This report found that many of the structural barriers which affect single parent families in general are exacerbated for those with disabilities.

These barriers include:

¹⁹ Papworth Trust, 2018. Facts and Figures 2018. Disability in the United Kingdom.

²⁰ <u>Scottish Government, 2021. Tackling child poverty - third year progress report: annex B - child poverty in families with a disabled adult or child.</u>

²¹ OPFS, 2022. Living Without a Lifeline

²² OPFS, 2022. Living without a lifeline: Single Parenting and the Cost-of-Living Crisis.

- access to employment.
- access to childcare.
- access to activities for their children.
- the costs associated with meeting their own and their children's specific needs.



My son has a disability, so this is causing me extra stress and anxiety, which affects my mental health. We are really struggling just to get by daily everything is expensive.

Kelly, single parent with son



Increased food costs - my autistic child must have specific items; nut allergies exclude some cheaper versions of foods. Additional heating and lighting costs due to my autistic child's sensory needs. Increased diesel costs when I rely on the car to access shops/lots of medical appointments.

Miriam, single parent with daughter

Moreover, changes in economic conditions, tax and social security are driving the fall in real household disposable income. The Financial Fairness Trust highlights that household debt is a major threat to the financial wellbeing of people on a low-to-middle income. Low-income families face the worst wage squeeze in modern history, leaving many households with little choice but to use credit cards to meet their most basic of needs. Consequently, the poorest households are left paying the

highest interest rates and charges²³. Parents are doing the absolute best for their families, but at every turn are faced with daily insurmountable challenges.

The Scottish Government's (SG's) second Child Poverty Plan 2022-2026 notes that single parent households face greater health inequalities due to the responsibility of looking after the complex health needs of their children:



Lone parents are at greater risk of poverty, are more likely to live in areas of deprivation and spend more of their income on basic living costs.

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It is a constant cycle of hardship often compounded by little or no support from family or friends.

Single parents often struggle with accessing affordable, flexible, high-quality childcare. In addition, if they have a disabled child who requires extra support based on individualised need, this often leads to higher costs for the family and can involve significant travelling to receive the appropriate support. Barriers to accessing quality childcare are worse for disabled children; parents and carers of disabled children pay higher than average costs, and three-quarters have reduced their hours or left their job because of difficulties accessing appropriate childcare²⁵. Through no fault of their own they are facing extremely difficult choices, all of which are having negative impacts on ever-diminishing household budgets and the mental wellbeing of the whole family.

Wellbeing

²³ Financial Fairness Trust, 2021. Debt Justice.

²⁴ The Scottish Government, 2022. *Tackling child poverty delivery plan* 2022-2026 - annex 7: equality impact assessment.

²⁵ UK Parliament, 2014. Report of the parliamentary inquiry into childcare for disabled children.



It's hard and I feel like a useless parent and a parent that cannot provide for my family. I must borrow money sometimes and then have to repay it... just once it would be nice to have enough money to put away to at least get a week's holiday.

Kitty, single parent of two children



I am depressed with the cost of living as I am not sleeping and feel overwhelmed all the time. I feel like a failure as a parent because I should be able to look after my child's additional needs without feeling like I am fighting for every little bit of support. It is so hard living on a low budget. There is never an end in sight.

Amita, single parent of a daughter

A recent survey by the charity Contact for Families with Disabled Children²⁶ of almost 3,000 UK families with disabled children during lockdown found that:

- At the height of the pandemic, almost a third of parent carers went without heating (30%) and food for themselves (37%). Half went without toys, presents and computer equipment for their children.
- 55% of respondents were shielding during lockdown. Because of shielding,
 30% report they got into debt or borrowed money, 15% got behind with

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²⁶ Contact for Families with Disabled Children, 2021. Counting the Costs.

mortgage payments, 10% used a foodbank for the first time and 7% lost their job.

- Nearly a quarter (23%) of respondents claimed Universal Credit and 40% of those said they were worse off since claiming, despite assurances from government that no one would be worse off.
- Nearly two thirds (61%) said that caring responsibilities meant they or their partner had given up paid work, on average losing £21,270 from their family income.

These findings chime with the feedback from parents highlighted in OPFS Living Without a Lifeline report²⁷.



My kids struggle mentally, and my depression is bad because it's such an overwhelming situation to be in. I need help to balance everything because it is hard coping with everything and being there as best I can for my children.

Adelaide, single parent with three children



I can't go out I suffer panic attacks ... my daughter has terrible anxiety. My son also has ADHD and feels the same way. It is a constant battle.

Clara, single parent with son and daughter

All of the pressures described have a knock-on negative impact on family wellbeing.

²⁷ OPFS, 2022. Living Without a Lifeline.

Single parents of disabled children are a marginalised and often invisible group who can feel isolated, alone, and stigmatised.



My son is autistic and must have specific items, but this is challenging with his food allergies and more expensive. Additional heating & lighting costs due to autistic child's sensory needs is very challenging. I feel like a failure, but every day is a struggle. Increased diesel costs when I rely on the car to access shops/lots of medical appointments for my son. It is never ending, and we are constantly anxious about costs.

Amber, single parent of son with autism



My daughter must eat a very healthy diet due to her genetic condition and the dramatic rise in my groceries bill is making life difficult. Junk food is cheaper to buy than fruit and veg, but she must eat healthy to stay safe... it is affecting how she is feeling and causing me additional stress to buy it on an ever-diminishing household budget.

Bernadette, single mother of daughter



My son is on the autism spectrum disorder so requires certain things and needs routine. It can be expensive with all the rising costs to provide what he needs, and it is constantly adding to my financial difficulties. I am very lonely and struggling with my mental health.

Lyn, single parent mother of some with autism

Loneliness and isolation can impact on people of all ages and can especially affect those living with a disabled family member due to lack of support and limited social interaction.

Services

Social Security reform is having a negative impact on all claimants, particularly single parents and more so, disabled single parents or those caring for a disabled child. At the same time, we have seen cuts to services. Recent academic research by Glasgow Centre for Population of Health and Glasgow Disability Alliance found that disabled family members are facing "significant reductions" in access to support workers, day care services and respite care²⁸. There are now fewer services since the COVID-19 pandemic and the cost-of-living crisis.

Housing

Single parent's families do not always have the option to choose the housing they want or require. OPFS recently carried out a consultation group with single parents

²⁸ Harkins, C; Burke, T; Walsh, D. 2023. The impacts of the cost-of-living crisis on disabled people: a case for action. Glasgow Centre for Population of Health and Glasgow Disability Alliance.

and found that housing was a prime concern²⁹. Participants who contributed to our Living Without Lifeline research raised many issues regarding housing, specifically relating to private rented accommodation. For instance, two fathers reported on their experiences of living in private housing accommodation. Housing costs were extremely expensive compared with social housing. They also said that their family's needs were often ignored by unscrupulous landlords, and this served as a deterrent in raising other concerns and problems. One mother described unmet repairs, and the uncertainty of housing tenure which meant that her family could not take ownership of their home and have the confidence in personalising their living space.

Our living environment affects us all but is particularly significant when considering the needs of a family living with a disabled child. A well-adapted environment is key, but often elusive when one considers the additional pressures which can arise when trying to access permanent and suitable accommodation from a reduced range of available housing.



I feel trapped in the private rental system. It is tenuous as the landlord could sell when they choose. Our house is not our own so there are things we cannot do to improve things. More help should be offered to individuals with disabled children to support them to purchase their own home.

Linda, single parent of two disabled children.

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As an organisation that supports single parents including disabled parents, we are acutely aware of the many difficulties that arise. Parents with a disabled child often face the challenges of living in cramped housing accommodation and struggle to

²⁹ OPFS, 2022. Living Without a Lifeline

³⁰ OPFS, 2022. Living Without a Lifeline Thematic Analysis and Quotes.

achieve positive outcomes. Research by Contact for Families with Disabled Children³¹ found that,

- Four in 10 (41%) families with disabled children have a home that does not meet their child's needs.
- Over a quarter (27%) say their home makes their child's condition worse or puts them at risk.
- Over a quarter (26%) say their home needs adaptations to meet their child's needs.
- One in five (21%) have feared losing their home in last 12 months.

When disability is combined with the experience of living in a single parent household, inevitably social disadvantages are magnified³²



I have three disabled children who will be dependent on me for years to come and need accommodation for them. The state would be saving a great deal of money if they were to provide us with support to achieve this.

Stephanie, single parent of three children



I have four children. Three of whom have disabilities. We need a home to call our own. I would like to stop having to worry about benefits stopping and further benefit caps.

Maggie, single parent mother of four children

³¹ Contact for Families with Disabled Children, NK. A decent home for every disabled child.

³² OPFS, 2021. Scottish Government Adult Disability Payment April 2021 Consultation OPFS Submission.

Policy recommendations

In line with many other charities such as, Disabled Children's Partnership, The Children's Commissioner England, Family Fund, Contact and others, OPFS is calling for:

The UK Government to:

- Encourage all political parties to prioritise the needs of disabled children and their families and to recognise that disabled children and their families are valued members of society.
- Introduce an Energy Social Tariff a discounted payment on disabled households for their energy costs. This will help ease the financial burden as we move into the colder winter months.
- Make a commitment to prioritise health and social care support for disabled children in their spending plans and making steps to close these funding gaps.
- Introduce a higher threshold level of payments to ensure a better standard of living as the current threshold is too low. We are calling for an increase in the top up for social security benefits to improve family outcomes.

The Scottish Government to:

- Introduce more financial assistance for children with autism given their needs and additional family costs are often more expensive given the equipment needed to cater for their individual sensory, emotional, physical, and developmental requirements.
- Increase support for families with disabled children in line with the Scottish
 Government's Child poverty Delivery Plan. The latter identifies six priority
 groups including disabled families, as they have the highest poverty levels.
 Immediate support should be given to these families as they have greater
 living costs and are given less support through the UK social security system.

- Build more accessible and affordable social housing and give greater priority to families with disabled children needing social housing to tailor their needs around access and practicality.
- Introduce Effective and cost of living strategies which are outcome focused and co-produced with single parents caring for a disabled child. Early intervention must be at the forefront of policy and spending at Scottish Government and Local Authority levels.

Local authorities to:

- Work with families, to use a strength-based model to achieve positive family health and wellbeing.
- Provide help by way of adaptations, equipment, or help with finding more suitable housing for disabled children which helps to improve their life outcomes.
- Provide greater access to respite services to families where a disabled with physical/ mental health or has behavioural problems. These services help to promote independence for children and young people and give the opportunity for parents to have a break and find support.

Conclusion

This report has collated some of the key findings from recent research, including our own, to highlight the main issues and challenges affecting single parents caring for a disabled child. As we have noted in this report, governments at all levels need to do a lot more to ensure that they meet the needs of the whole of society, disabled and non-disabled alike. Society's institutions (such as, housing, health and social care, welfare services, childcare, and employment) should consider greater wraparound of services to prevent families coping with disability from being constantly in crisis mode or falling through the net. They deserve the help that they require when they need it the most.



If you have any questions about anything in this report, please contact us at:

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